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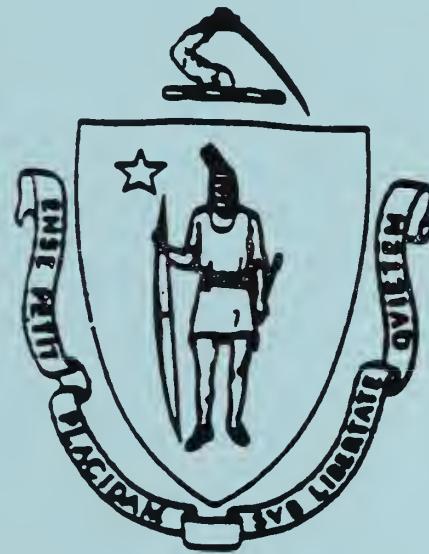
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Executive Office of Health and Human Services

Department of Mental Health
Marylou Sudders, Commissioner



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THE DMH CORE CURRICULUM

Office of Clinical and Professional Services
The Training Program
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COMMONWEALTH OF MASSACHUSETTS
Executive Office of Health and Human Services

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THE DMH CORE CURRICULUM

PROMOTING FAMILY COLLABORATION IN THE CHILD/ADOLESCENT MENTAL HEALTH SERVICE SYSTEM

June, 1997

Office of Clinical and Professional Services
The Training Program

INTRODUCTION TO THE SERIES

This is an era of exciting challenges in healthcare. The Department of Mental Health is in the forefront of these changes with new initiatives in managed care, privatization, and comprehensive community support systems.

To ensure the highest quality of care during this period of change, the Commissioner instructed that a DMH Core Curriculum be drawn up, and that within a three-to-five year period that every DMH state and provider employee be instructed in the components of this curriculum. With the full support of the Deputy Commissioners and the Area Directors, DMH state and provider managers and staff, and consumers and family members developed the Core Curriculum in the Summer and Fall of 1992.

Since many agencies already provide instruction in various aspects of the Core, a state-wide needs assessment was completed in the Summer and Fall of 1992 to determine which components of the Core needed more immediate attention. Again, DMH state and provider agencies, consumers and families participated. Eight areas were identified as needing more precise clinical practice guidelines: the role of the consumer, human rights, the role of the family, dual diagnosis (mentally ill/chemically addicted), alternatives to restraint and seclusion, psychosocial rehabilitation, multicultural issues, and gerontology.

In the Fall of 1992, Clinical Practice Guidelines Workgroups for these eight areas were convened. Consumers, families, and DMH state and provider employees participated in developing these practice guidelines. Each group was asked to develop the basic guidelines for practice in its area, to write a training manual on that topic, and to outline a training for its area of expertise.

This manual, the previous manuals, and those to follow present the DMH clinical practice guidelines for the basic components of the Core Curriculum. It is hoped and expected that each DMH state and provider agency will incorporate these guidelines in practice so that every DMH consumer can expect a reasonable and consistent standard of care in any community in the Commonwealth.

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January, 1997

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I. Introduction

- *Throughout this manual the word **family** may refer to biological families, adoptive families, step-families, extended families, foster families and/or any other individual or group of individuals who play a significant role in the life of the child or adolescent.*
- *Throughout this manual the word **service provider** refers to all staff members working in programs or agencies, private or public, that provide mental health services. This includes DMH case managers and other DMH staff members.*
- *Collaboration, in the context of this manual, is the formation of a working relationship between service providers and parents that fosters joint decision making about the treatment of a child or adolescent.*
- *DMH believes that through families and service providers sharing expertise and forming common goals and approaches to treatment, children and adolescents are more likely to receive appropriate care while maintaining and strengthening family bonds necessary for positive familial relationships.*

Over the past few decades there have been dramatic changes in the way that mental health service providers view the roles of families in the treatment of children and adolescents with serious emotional disturbance, as well as the way families perceive their roles. The silence and fear of stigma that have historically surrounded having a child or adolescent with serious emotional disturbance have increasingly been replaced with family involvement and advocacy in treatment. Changing attitudes of both families and service providers have made it possible for family collaboration to be recognized as a useful tool in

the treatment of children and adolescents. Theoretical orientations have shifted from those which tended to hold parents solely responsible for the emotional problems of children and adolescents, to contemporary thought which “acknowledges that many factors, biological, social and psychological, may contribute to a child’s disorder” (Friesen & Koroloff, 1990).

This manual is intended to be helpful in working with families regardless of the factors contributing to the emotional disturbance of their children and adolescents. In some instances, family dynamics or the specific actions of family members may have contributed to some youth’s emotional problems. In other instances, families may not have known how to best respond to their children’s emotional disturbances, and therefore responded in a way that may seem inappropriate to service providers. Circumstances such as these make the work more challenging but should not stop the service provider from striving to develop a collaborative relationship. Service providers need to recognize that family members are usually doing the best they can for their children given the family’s circumstances. Virtually all families love their children, and all parents want to be good parents. No family is perfect, but even families with overwhelming problems can make meaningful contributions to seeking powerful and lasting solutions to their children’s problems.

Although the need for collaboration between service providers and families has gained widespread acceptance in recent years, training in and accountability for collaborative practices have lagged behind. Confusion still exists about what it means to have collaborative relationships, what they entail, why they are necessary, whether they are always possible, and what service providers need to know and to do in order to form collaborative relationships with the families of children and adolescents with serious emotional disturbance. This introductory chapter will define the terms *family* and *collaboration*, and will explain the values that govern collaboration between families and service providers.

What is a family?

Families have always existed in many different forms and have always performed various roles in the lives of children and adolescents. Throughout this manual the word *family* may refer to biological families, adoptive families, step-families, extended families, foster families and/or any other individual or group of individuals who play a significant role in the life of the child or adolescent. The implication of this broad, inclusive definition of *family* is that the significant people in the child's life that service providers work with may extend beyond those who have legal responsibility for the child or adolescent. The service provider's task is to work with those who have legal responsibility for the child or adolescent and to determine if there are other individuals with significant connections who should also be engaged in helping.

In broadening the concept of family, service providers must proceed with caution in deciding whom to involve in the child's treatment and evaluate the legal and clinical ramifications of involving people beyond the legal guardians of the child. For example, it may not be appropriate to involve foster families in all of the ways that other kinds of families are involved. Depending on the specific circumstances of the relationship, foster families may or may not have the same kind of history or future together that other kinds of families have. Programs should initially work with the family as defined and determined by the legal guardian, and should expand family involvement as deemed appropriate by the child and legal guardian.

The Department of Mental Health (DMH) believes that it is essential for service providers to understand that all families are unique and have special needs and responsibilities. For example, step-families and blended families have become increasingly common. Adoptive families face particular challenges. Many children and

adolescents are primarily connected to grandparents or other relatives in addition to or instead of parents. Some children live with foster families because of protective issues in their primary families. Other children and adolescents have no permanent family.

Families also differ in their cultural, ethnic, and racial backgrounds, their traditions, and in ways of expressing these differences. “Service providers need an awareness and acceptance of cultural differences, an awareness of their own cultural values, an understanding of the ‘dynamics of difference’ in the helping process, a basic knowledge about the client’s culture, knowledge of the client’s environment, and the ability to adapt practice skills to fit the client’s cultural context” (CASSP, 1989, p.32).

Positive Adoption Terminology

- Use the word “*birthparent*” instead of “*real or natural parent*”
- Use the word “*child with special needs*” instead of “*hard to place child, handicapped child, or problem child*”

What is Collaboration?

Collaboration, in the context of this manual, is the formation of a working relationship between service providers and families that has as its goal the fostering of joint decision making in regard to the treatment of a child or adolescent. Ways to reach collaboration need to be discussed in depth between service providers and families in order to address the specific needs of the family and to involve the family at a level the family can sustain. Collaboration with families is a means to an end - the end being to deliver the most appropriate and effective services possible for the child or adolescent and his or her family.

The Department believes that the concept of collaboration in treatment is built on the premise that most parents have special expertise about their own children, while professionals have the formal knowledge, skills, and training to treat emotional disturbance. Collaboration is also based on the premise that psychologically the family

remains central to a child's self esteem, self-concept, and motivation for change, regardless of where the child resides and regardless of the dynamics of a particular family. DMH believes that through service providers and families sharing expertise and forming common goals and approaches to treatment, children and adolescents are more likely to receive appropriate care while maintaining and strengthening family bonds necessary for positive familial relationships.

In some cases, children may be separated from their families because they have been abused or neglected and parents may be unable to be directly involved with their children. When the Department of Social Services has custody of a child or adolescent, the service provider must follow DSS's lead concerning involving the family, consistent with Massachusetts law and DMH regulation and policy. However, service providers should communicate with DSS if they believe a different level of family involvement would be beneficial for the child. It is often the case that children in permanent custody of DSS have siblings also in the care of DSS or still in the care of the original parent. Whenever possible and clinically appropriate, programs should work with DSS to establish opportunities for these children to have access to one another, even when parental involvement is not considered appropriate.

It should also be acknowledged that for some children and adolescents, there is no family to involve. For these children, programs should work with DSS to identify an individual in the community who could provide a non-professional nurturing relationship. The importance of this kind of relationship as a healing force in a child's life cannot be overstated.

Values and Beliefs Governing Collaboration

There are many values and beliefs that are helpful for families and service providers to share in order to form and use a collaborative relationship. Below are six value statements and beliefs, identified by families and service providers, that lay a foundation for building collaborative relationships.

- **The family should be a child's first and most significant care giving entity.** A family is a constant in a child's life while services and providers frequently change. Even children in residential treatment usually return to their families as soon as they have the opportunity to do so. It is therefore essential and in the child's best interest to maintain and promote the child's connections and bonds with the family and the home community.
- **All families have strengths and weaknesses.** Interventions should always build on family strengths. The service provider has the responsibility to help families identify and recognize their strengths. Service providers should apply their training in a way that optimizes the strengths and resources unique to each family. Service providers can foster change in family behavior in a manner that is collaborative and respectful.
- **Parents/caretakers are usually experts about their own child and family.** Parents often know their child's likes and dislikes, moods, strengths, and needs. They also know what interventions have been tried with their child in the past, what has worked and what hasn't worked.
- **Service providers can be valuable consultants to families.** In addition to their roles as diagnostician, administrator, therapist, etc., professionals are also able to share their knowledge about emotional disorders, resources in the community, and effective interventions to help families make informed decisions about their child's treatment and their child's future.

- **Programs should be family friendly and accessible.** Programs should identify and then overcome or minimize obstacles to family involvement such as restrictive visiting policies, geographic barriers, cultural differences, language barriers, and time constrictions. It is the program's responsibility to create an environment in which families feel comfortable and participate.
- **Service providers should have respect for the diversity of families in terms of race, ethnicity, culture, religion, education, and socioeconomic situation.** Professionals should demonstrate competence in understanding, and providing services to, a diverse group of families.

II. Understanding the Impact of having a Child with a Serious Emotional Disturbance

Mother of a fifteen year old:

I've been his best friend. It is very difficult to be his best friend and his mother. I'm the one he hangs out with and goes places with. His sister is embarrassed, and won't bring friends to the house because she's embarrassed. She doesn't talk to him, they fight. She wishes he didn't have this illness even though she knows he can't help it. There is a lot of screaming and yelling and fighting in my house because of it.

The hardest part is to watch Peter in public. People who don't know him think he's weird. Sometimes when they don't know I'm his mother I overhear what they say about him. They say things like "that weird kid". There's nothing you can do about it. I really wish people could be more understanding. That people could realize, "that could be my child -- that could be me".

What I'd want to say to someone with a child with a disability is that you will go to a lot of psychiatrists, and psychologists, and therapists. No matter what, you have to go by what you think, because no one knows your child better than you do. Trust your instincts. Sometimes things the psychiatrists recommend aren't the right things. Trust that you know best.

Families report that the most effective interventions and supports they have received are from those service providers who understand the impact on a family of having a child with an emotional disorder. Understanding the family's experiences gives professionals a perspective that enables them to respond to families' needs. It also helps the program recognize that oftentimes, families' strong reactions and emotions are normal responses to a traumatic experience. The vignettes included in this chapter were written by family members of children and adolescents with serious emotional disturbance, and were

submitted for use in this training manual. All identifying information has been deleted or changed. Additional family member vignettes are included as an appendix to the manual.

Among the issues that families find most helpful for service providers to understand are the levels of grieving that many families go through; the issues of loss that families face; the burden of care that having a child with an emotional disturbance places on a family; and the effect of one child's difficulties on siblings. While it is extremely important to acknowledge and understand the tremendous stress and loss that many families face, it is also important for the service provider, family and client to keep sight of what strengths remain.

Grief

Parents of an eighteen year old

Mother - "It's just like someone has died because this is not our little girl anymore."
Father - "We don't know who she is from one minute to the next. I dread people asking how our kids are doing. What can I say?"

When families learn that their child has a serious emotional disturbance, they grieve for the loss in ways similar to those of grieving over a death. However, the normal stages of grieving: shock, denial, depression, anger, acceptance and coping are complicated by the uncertainty of the diagnosis and progression, and the stigma of mental illness (Spaniol, Zipple, & Lockwood, 1993). For example, the

uncertainty associated with the course of emotional disturbance can cause families to cycle painfully between hope and despair. Uncertainty can hinder acceptance and also cause feelings of guilt and self doubt. Some families may blame themselves for the child's illness. Families can be irrationally plagued with regrets. Families commonly think that "if only" they had tried a different school, a different therapist, a different parenting style, "if only" they had done more, the situation might have been averted.

Sometimes, once appropriate services have been identified for a child, families first experience a sense of relief, and then get in touch with how angry they are. This anger can take many forms including over-concern, disappearing, and displacing anger on current or past service providers. It is important to acknowledge this anger and to provide support for it as a temporary state.

Blame

Families often encounter blaming attitudes about their child's illness from a number of different sources, including: extended family, friends, neighbors, mental health service providers, and educators. Because the causes of emotional disturbance vary greatly and are not fully understood, blaming families is common. Blame is not only unhelpful, but can impede a family from seeking solutions and can place additional burdens on a family that is already experiencing stress.

Mother of a fourteen year old:

We didn't bargain for this and people treat us like we did something wrong. Why doesn't anybody think of mental and emotional problems in the same way they think of physical problems?

Stigma

The stigma of mental illness can cause families to hide their child's disorder from potential natural support systems such as neighbors and extended family. Even those families who do not hide their child's disorder sometimes face family members who deny the problem with the same resultant lack of support. Working through the impact of a

Mother of a seventeen year old:

We put him in McLean Hospital. While he was in the hospital for five weeks, he didn't receive one get well card. At the same time a kid was getting a kidney transplant and there were fund raisers and everybody sent in get well cards and his name was across the street downtown. My kid didn't even get a get well card from his guidance counselor or any of his teachers.

child's emotional disturbance can be more difficult without the help of these natural supports. People .

tend to treat children and adolescents with emotional disturbances differently from children with physical illnesses. While neighbors and family members typically rally around and support families with a child with a physical disability, communities do not typically respond in the same way towards a child with an emotional or behavioral disability.

Issues of Loss

Families of children with serious emotional disturbance experience many different kinds of losses. The change in their child's personality not only creates a sense of losing the child who is familiar to them but may precipitate a whole "lifetime of losses" (Johnson, 1988). Some of the losses experienced by families are "...loss of a child's personality; loss of a child's role in the family and in society; loss of the child's joy and pleasure in life; loss of potential, talents and competence; loss of a gratifying relationship of

reciprocity within the family and with others; loss of a child's hoped-for future; and, in some cases, actual loss of a child who wanders off to disappear among the homeless population or who commits suicide" (MacGregor, 1994). Other losses often include:

- the loss of financial resources due to the significant costs of care and treatment

Mother of a ten year old:

When I look at the family album, I see the family we could have been and were supposed to be. The future looks so bleak and full of worry. We really don't look forward to much anymore because this takes up so much of our time and energy.

Mother of a seventeen year old:

My ex-husband blamed me and I blamed him. We tried everything, being tougher, being easier and nothing worked. Money became a big problem because there was always another doctor or school. I think that we were so frustrated that we took it out on each other. Then the counselors started saying that we had a bad marriage and that was the problem with our kid. We got divorced but it sure didn't make anything better.

- the loss of the normal functioning of the family, e.g. taking vacations, inviting friends and family to the house, going out to dinner, spending holidays with extended family and friends
- the loss of a marital relationship, as there is an unusually high incidence of divorce among parents of children with serious emotional disturbance
- the loss of friends who do not understand mental illness and who cannot be effective supports
- the loss of a sense of physical safety when a child or adolescent's behavior is violent or aggressive
- the loss of sense of self as an effective individual and parent

Family Burden of Care

“Family burden” is the measurable social, psychological and economic cost associated with the care of a family member that is in excess of the cost associated with normal care giving. The extent of the family burden will vary according to social and psychological circumstances of the child and family, as well as the family’s resources, supports, and the services they receive. There is an “objective” burden which focuses on the demands on time and money, as well as “subjective” burden that refers to the extent to which a family member feels burdened by living with a family member with serious mental health problems (Tessler & Gubman, 1987; Brannan, Heflinger & Bickman, 1996).

Service providers are encouraged to evaluate and work towards reducing the burden of the families they work with. Though often children’s illnesses cannot be “cured”, if providers can reduce the burden of care, progress will have been made. Even children and adolescents of families undergoing extreme stress may be able to remain in the community if the family’s capacity to care for the child or adolescent increases, and the burden of care diminishes.

The Impact on Siblings

Both as members of the changing and adapting family unit and as individuals with their own relationship to the child or adolescent with emotional disturbance, siblings are profoundly affected. Many of the same issues that affect parents also affect siblings, such as guilt, loss, changes in family routines and priorities, and stigma. Specific issues that may affect siblings more than other family members include the response of their peer group, concern about their own susceptibility, increased household responsibility and exacerbation of sibling rivalry (Gubman & Tessler, 1987).

Sister of an adult

I hate him for what he did to my parents and me. I didn't really have a childhood because we never knew what to expect. My friends didn't want to come to the house and I guess I really didn't want them there because I felt so nervous. Our name was in the paper when he got in trouble with the police. I'm glad he's gone. We don't even talk about him anymore. My parents stay at home most of the time. They don't even have friends anymore - no one knows what to say.

In order to help siblings with the issues that are common to all family members as well as those that affect siblings in particular, siblings “need to be acknowledged and encouraged to participate in the family sessions” (Modrcin & Robison, 1991). Siblings need information about their brother or sister’s emotional disturbance and the course of treatment to help them answer the questions they have.

III. Roles of Family Members of Children with Serious Emotional Disturbance

Family members play many different roles in the life of a child. The different roles that family members play have the potential of benefiting the child or adolescent, the family itself, and the mental health system (Spaniol, Zipple, & Lockwood, 1993). Collaboration between service providers and families requires a mutual respect for each other's roles and responsibilities in the provision of services. This chapter outlines the most common roles of family members of children with serious emotional disturbance.

Decision Maker

Parents and legal guardians are the ultimate decision makers for their children. Parents make decisions for their children and adolescents regarding education, medical care, religion, discipline, and a host of other day to day issues. In addition to the decisions in which service providers are required to include parents, the broader decision maker role of the parent should be maintained as fully as possible while a child is receiving services. In some circumstances, parents' rights to make decisions may be limited for 16 and 17 year olds.

Care Giver

Families form lasting emotional and psychological bonds with their children. These bonds continue even in the face of hardship, separation, or other traumatic events. Families should be the primary care givers. This care giving role can become complicated when a child has an emotional disturbance. Although the care of a seriously emotionally disturbed child or adolescent is often shared between families and professionals, the family remains the most significant, and the most consistent care giving entity.

Advocate

Family members are advocates for their own children. In addition, they can be strong advocates for systems' change. Family members are often the most effective spokespersons for children with serious emotional disturbance and their families because they understand the entire family's needs and the shortcomings of the current system of care. They also have a personal investment in the issues. Service providers benefit from family advocacy because families can "bring pressure to bear on the mental health system and its funding sources that professionals alone could never bring about" (Spaniol, Zipple, & Lockwood, 1993).

Both family members and service providers report that advocacy and assertiveness are sometimes seen as aggression by service providers. On occasion, advocacy does reflect aggression born of a family's outrage and frustration at a system that has failed to meet some or all of the child's needs. At other times, assertiveness is mislabeled as aggression by the systems that are targets of change. Regardless of whether the family is being aggressive or assertive, providers need to recognize the willingness of families to take a stand as a strength and assist families in developing their advocacy skills. Service providers do this by sharing information, discussing choice of strategies, and fostering positive, effective communication skills. Service providers can also refer families to family advocacy groups such as the Parent Professional Advocacy League (PAL) and the Alliance for the Mentally Ill (AMI).

Historian

Most family members know their child's life history, strengths and weaknesses, likes and dislikes, and reactions to life stresses. They know what interventions of the mental health system have been tried before, what has been helpful, and what has not..

As experts on their child's history, many family members have expressed the concern that case records sometimes do not accurately portray the child's and the family's history. Service providers should ask family members to determine whether what is written in the case record is accurate from their perspective. Sometimes one version of events has been accepted as true without soliciting the parent's version. Service providers should allow family members the opportunity to review the case record and to give context to what is written in the case record or provide corrections to it if they do not feel it is accurate.

Service Coordinator

Family members often coordinate the care of their child. They see that their child receives necessary services by brokering, advocating, transporting, and maintaining a constant surveillance on the system on behalf of their child. For children and adolescents who do not receive case management, the family member may be the sole person playing a coordination role among the agencies providing services to their child. Families are ultimately responsible for seeing that their child's wants and needs are met. They are also the only constant members of the care team.

Protector and Guardian

Family members try to protect their children from harm. Oftentimes, children with emotional disturbances are susceptible to misunderstanding, stigma, and teasing. Parents often spend a great deal of time and energy protecting their child or adolescent from people who do not understand emotional disturbance, peers who tease or shun their child, and members of the public who stigmatize and are often insensitive to emotional disturbance.

Teacher and Trainer

By sharing their stories, family members can break down stereotypes, help service providers understand the impact of having a child with an emotional disturbance, as well as help other families to realize that they are not alone. Family members need to be encouraged and supported so they are able to use this powerful role in settings such as family support groups, policy task forces, legislative advocacy, and in training service providers to work with other families.

All families can not perform all of the above roles all of the time and this list should not be construed as setting expectations. Some families perform well in some of the roles while not being able or willing to fulfill others. Families have varying resources that strengthen or weaken each of these roles. Families can be so over-burdened by the stress their responsibilities place on them that they can not do more. In addition, there may be legal restrictions that interfere with the roles that family members usually play.

IV. Collaborating with Families

The *first* stage of collaboration involves orienting family members to the program, the services to be provided, and to the staff who will be providing services. In this first stage, family members and service providers are getting to know each other, and communicating and negotiating expectations. This should include: a discussion of how each party sees the goals of treatment; a discussion of obstacles to treatment goals; how the service provider and the family will work to overcome obstacles; and what the family expects from the service provider and what the service provider expects from the family.

Based on past experiences, some families may be reluctant to trust service providers and some service providers may be reluctant to trust families. Families who have felt blamed in the past are more likely to interpret providers' behavior as blaming. For various reasons, some family members may come across as withdrawn or disinterested to service providers. Other families may seem aggressive and sometimes even manipulative. Service providers should confront their own concerns about the family and, if necessary, address the reasons why a family is distrustful. This should include a review of the family's past experiences with service providers. It is important for all parties to remember that different people enter relationships at different rates and trusting relationships can only develop over time.

The following six issues were identified by Modrcin and Robison (1991), as issues to consider when working with a family that has a child with a serious emotional disturbance.

1. *A family does not anticipate the onset of a severe emotional disorder in one of its children.*
2. *These children present a unique set of developmental challenges to which families must adapt and adjust.*
3. *Families experience a loss as they begin to understand their child's disability.*
4. *Families of these children are faced with long term support issues that extend and modify the parenting role beyond expected years.*
5. *Families vary in their response to stress.*
6. *Families will need a range of coping strategies and resources to manage the stress in their lives.*

Cultural differences can also impede the fulfillment of collaborative relationships between families and service providers. It is important for service providers to recognize that “cultural and family factors influence the validity of diagnostic criteria, treatment outcomes, interpretation of psychological tests, and the identification of significant caregivers. The more different the (family) is from the provider’s culture, the greater the opportunity for the provider to misinterpret behaviors” (Adams, 1996). To combat this potential for misinterpretation, service providers must first recognize it. Paying careful attention to an individual family’s norms, values and opinions is the first step towards cultural competence.

Although DMH recognizes that open communication between families and service providers is an important step towards collaboration, there are specific issues about confidentiality and how information is shared that need to be clearly and sensitively acknowledged. These include:

- Families feel at a disadvantage when staff members have information about their child and family that the family does not know has been shared. Practice regarding whom information is shared with and why should be explained to families. Sharing information about a child and family among staff members should only be done on a “need to know” basis.
- In some cases reporting requirements such as those governing abuse and neglect or the duty of a professional to notify the victim if a client threatens harm (Tarasoff) may be limitations to confidentiality between service providers and family members.
- Information given by a child during therapy sessions may remain confidential between the child and his or her therapist.

The *middle* stage of collaboration consists of joint planning and ongoing communication during the family’s involvement with services. Families and service providers should discuss how to ensure on-going communication, as well as the mechanisms the program uses to resolve concerns and conflicts between family members and service providers. Families want to be dealt with in an open and honest manner, even when the subject matter is difficult. Real respect between service providers and families comes from struggling and grappling with the very difficult issues presented by these children and adolescents. The courage to ask for honest feedback from parents, and give them honest feedback about how they are seen is the basis of real collaboration.

In residential programs, service providers should seek ways to involve families in every day activities when appropriate, as well as ensure families flexible access to their children and to program staff.

In the Department of Mental Health system, the Individual Service Plan (ISP), which identifies treatment goals, and the Program Specific Treatment Plan (PSTP), which

defines the steps towards the goals, are important tools for service providers and families to use in order to ensure that goals are clearly stated, mutually agreed upon, and that the progress made towards reaching goals is monitored. Collaboration in this process is an opportunity to make sure that all concerns and viewpoints are addressed. Parents with legal guardianship must be invited to treatment planning meetings, and must be informed of and have the right to attend periodic reviews of their child's or adolescent's treatment plan. In addition, other individuals, upon the invitation of the child/adolescent, have the right to participate in the treatment planning process.

It is important to both inform parents of their rights concerning participation in treatment planning and also to create an environment that fosters full parental participation. Families feel more comfortable participating in service planning when service providers acknowledge the family's expertise about their children and clearly convey that they value family member input. Meetings should be scheduled at times that are mutually convenient for family members and staff, and family members should be encouraged to bring another person to meetings for support, if they wish to do so.

Family Support Groups

Not only are family support groups one of the most important sources of information and support available to family members, but with the proper preparation, attending a parent support group can also be a valuable experience for new service providers, and periodic refresher for veteran workers. Attending a support group meeting allows providers the opportunity to hear parents tell their stories on their own terms and in their own words.

The *last* stage of the collaborative relationship occurs when the family moves from one service to another, or transitions out of the system of care altogether. This should be a planned rather than an abrupt end, and service providers often continue to have a relationship with the family. Continued contact between service providers and families is usually dependent on building a strong relationship while the family is receiving services.

Service providers can ease the transition out of the services they provide through careful planning and by acting as a bridge to the new program or services. For service providers, this may mean participating in the orientation to the new program or services. For case managers, this may mean helping to identify resources beyond what the service providers offer, or helping with the transition to adult services. In so far as the family and child is willing and provider resources permit, providers are encouraged to do informal or formal follow up with families.

V. Multiple Agency Involvement

Many children and families are simultaneously receiving services from both public and private agencies. Negotiating the different services and procedures of the multiple agencies and working through the complexity and the inadvertent conflicts that arise in service planning can be confusing and frustrating for everyone.

Different agencies are bound by different regulations and policies. Not all agencies involve families in services in the same way. For example, agencies such as DSS and DYS may have custodial arrangements with the children they serve and may hold certain decision making rights that parents usually have. Parents with legal custody have special legal rights in regard to educational services that cannot be overridden. In addition, the courts may have set certain conditions or expectations about family involvement. Service providers should be clear regarding any constraints to family involvement or any mandates for family involvement prescribed by the courts or other agencies. Providers can help families devise strategies for advocating for themselves and assist in such advocacy when appropriate.

Service providers can help families navigate the complexity and confusion of being involved with multiple agencies. By knowing about policies and regulations of other agencies and working collaboratively with them, it may be possible and beneficial to integrate services. In order to lessen the possibility of conflicting treatment goals and approaches, and in order to foster collaboration, open, honest meetings should occur at the onset of treatment. These meetings should include the child or adolescent, the youth's parents, and the workers/staff members from the different agencies involved. Some of the questions that a meeting such as this should attempt to answer are:

- What are the treatment modalities of the various program?
- What are the parents' expectations? What are the expectations of the child or adolescent?
- What are the expectations and rules of the other agencies? What are the restrictions placed by other agencies? Is there room for negotiation?
- To what degree do the other agencies involve parents in decision making? What, if any, are the limitations to parent involvement?
- How can the different team members work out these issues?
- How can ongoing communication be assured among all parties?

VI. Legal Issues

Families will have questions about legal issues and their legal rights in regard to services provided or funded by various public and private agencies. Service providers should encourage families to learn about these rights and should help them exercise these rights. Some common questions from parents include but are not limited to:

- Which program meetings or service planning meetings must parents be invited to?
- Must parents sign off on an Individual Service Plan (ISP)? What about a Program Specific Treatment Plan (PSTP)? What if the parent does not agree?
- What treatment and medical records can parents access?
- What is the process for accessing these records?
- When a child is in a residential program, do parents retain the right to make decisions about the methods used to discipline their child?
- What rights do children and their parents have concerning choices about education?
- With whom can parents/guardians safely consult about their rights?

Service providers should have the answers to the most commonly asked legal questions and these, along with program policies, should be clearly conveyed to families in a program handbook. Service Providers should also convey information orally and be prepared to discuss information presented in the handbook with families. For more specific or individualized information, providers should refer families to other sources for answers to their legal questions. The answers to specific questions may vary depending on what type of program the child is involved with (inpatient, residential, day treatment, etc.) and what agency, if any, licenses the program or services (DMH, DPH or OFC).

The Mental Health Legal Advisors Committee (MHLAC) produced the first edition of a manual entitled “The Handbook on the Legal Rights of Minors” in the Spring of 1996. This manual is a good source of information about mental health services for children and

adolescents. In addition to describing which mental health services are provided by which state agencies, the handbook provides information on topics such as participation in treatment planning; guardianship issues; treatment rights; admission and commitment; civil rights; restraint, seclusion and room restriction; confidentiality and privilege; access to mental health records; cash assistance benefits; health care coverage programs; special education; and legal resources. Although the handbook was written specifically with the rights of the child or adolescent in mind, it also ably covers the rights of parents and guardians.

VII. Future Planning

Most families create a vision for their child's adult life, and often start to chart a course to achieve that vision from very early on. This vision for the future stems from the child's and the family's hopes and dreams of what is possible. Hopes and dreams translate into goals and aspirations that children and families strive to accomplish.

Planning for the future is a complicated process for all children and families. It is an ongoing process that adjusts for changes in what the child and family want, in the child's level of functioning, as well as in the circumstances and resources of the family. For children and adolescents with emotional disturbance, planning for the future is more complicated. Worry about their child's future is a major stressor for families of children with emotional disturbance. Families worry about what educational and vocational goals are realistic for their child; whether their child will have meaningful relationships as an adult; who will assume the role of caretaker in the future; what role siblings will play in the child's care; and how to finance the long term care of the child.

Other reasons that planning for the future is more complicated for children with emotional disturbance are:

- crises may occupy all of a family's time, and limit planning to the present or very near future;
- variability in functional ability makes it difficult to assess the child's future potential; and
- because of repeated stress, failure, and frustration, it may be difficult for families to form a positive vision.

Planning for the future can be facilitated by a deliberate and thoughtful process including many natural and professional support resources. As planning for the future . . .

should be driven by the child's and the family's needs, preferences, and interests, service providers should tune into families' specific concerns about the future. They need to listen to what the families' hopes, dreams, and aspirations are for their children, and help children and families find realistic ways to achieve them. Service providers should help families not only to identify their strengths, but also to incorporate those strengths into their daily lives and future plans.

As adolescents become young adults they naturally become more independent. Often, letting adolescents take increased control over planning their own lives is difficult. This is true for all families but is especially difficult for families of adolescents with emotional disturbance. Service providers and families should help adolescents take more control over their lives while maintaining family involvement in planning and decision making. Adolescents also need preparation for adult relationships with their families or families they may join or form. Especially for youth who have not had a family or who have been separated from their families, work must be done to help the youth understand the role of family, reasonable expectations of family, and that all families have problems and limitations as well as strengths and resources.

Since many of the youth who are eligible for DMH Child and Adolescent Services will not be eligible for DMH Adult Services, service providers need to help families think through what solutions are available beyond what they can provide. Other resources, including natural supports and resources provided by other state and community agencies, must be identified to help children and families plan for safe and productive lives. For those youth who will likely be eligible for DMH Adult Services, the Service Provider should help facilitate the eligibility process and do so in a timely manner to ensure a smooth transition.

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APPENDIX A

FAMILY MEMBER VIGNETTES

The vignettes included in this manual were written by family members of children and adolescents with serious emotional disturbance, and were submitted for use in this training manual. All identifying information has been deleted or changed.

Mother who terminated her role as adoptive parent:

First off, it was a nightmare from the beginning that you don't wake up from. We had a large specialized foster home. Over 60 kids have been in and out of our home. We got Maggie at ten days old. We were hoping to take a break from sexual abuse issues. She was a high risk infant and her behaviors were characteristic of cocaine / crack withdrawal. Her mother had OD'd at eight months, and Maggie had tested cocaine positive at birth. She was reactive, she had constant tremors and was constantly crying. We were not able to hold her, cuddle her or feed her the way you would any other baby.

As she grew, we learned how to let the day revolve around her. It was a natural evolution to live around her inadequacy. You get into such a routine, and you're not able to break the chain. You feel inadequate because you can't respond to her feelings of inadequacy. Everybody feared her. The older she got, the more we were afraid of her capabilities, and the less capable we felt. The feelings of inadequacy grew and grew. People would look at us and say "You got her as an infant...What did you do wrong?"

When she was four years old, she threw our littlest one down the cellar stairs. Our baby was in the hospital with head trauma for four days. It got to the point that there was no choice but to terminate our parental rights. Either everyone else had to leave the house and let her come home, or she couldn't come home. She is not in the house any longer. We terminated the adoption.

Who is going to be her historian now that she's not with us any longer? She has no history any longer, we were the only people that knew everything about her. I remember handing over her birth certificate and crying my eyes out. I remember every single detail of the six years she was

with us. Who's going to be her advocate now? There's a big void where we once were in her life. Nothingness. No one to pick her up and touch her.

We pray for her every day. We look at her pictures around the house. We don't know whether to take them down or to leave them. It's an ache that we'll have forever. It's like she's dead, but she's not. Christmas was very hard. We still have all of her Christmas ornaments. We're trying to find something good out of all of this, but it's hard. We miss her, but we're not sorry that she's not here. The thought of going back to living how we did when she was here is unimaginable.

It's very difficult coming to grips with our inability when it came to her. We've had sixty kids come through our house. We've never had a disaster. I know it's nothing we did in Maggie's case, rather it's what we couldn't do for her. I don't know what more we could have done.

Our three year old, the youngest that was thrown down the stairs, needs a liver transplant. No one would ever say that's our fault. But when it's an issue above the shoulders people look at you and think it's something you did. We got fingers pointed at us. "You had to have done something". That was the hardest thing to swallow. No support, no validation, no encouragement, no hope that someone could do something to help.

We'll never hug her, or smell her, or touch her again. When you put in so much energy, you want rewards later on and we'll never get them. She should be with us and she's not. She should be happy and she's not. Everyone loses.

Father of a twenty year old:

I'm sick of filling out forms and talking to doctors and social workers. All our insurance has been used up. We used up our savings trying to keep up with therapists bills and they didn't even help - kept wanting to know what was going on at home, why we were so angry, and I loved it when they'd explain how to 'modify behavior', yeah, right, like charts and rewards ever made a difference!

Brother of a sixteen year old:

I'm tired of seeing my mother always trying to do more, finding new books and new doctors. I know that she'd do the same for the rest of us, but even holidays are uncomfortable because you know it's on everybody's mind.

Father of a sixteen year old:

Sometimes I don't even want to see my own kid. I feel like a lousy dad. The people at the hospital look at me like I'm some kind of scummy person and even though I know that I'm not, it still makes me feel like a bug in a jar.

Father of a twenty-one year old:

You know, I do love my daughter, but it's a relief to have her out of the house. I don't miss having to hide money or credit cards, even bills where she could get an account number. We hated to answer the phone because it usually meant more trouble. My wife and I have a very strained relationship due to everything that has gone on and I guess if I didn't see my daughter for two years, I wouldn't miss her.

Mother of a nine year old:

Someone in social services once told me that they could help me with money when I tried to explain how exhausting it was being a full time working mom with an emotionally disturbed child living at home. I may be single and not make much money but I don't need money. What I need is an hour to myself once a week.

Mother of a six year old:

My mother and sometimes friends don't understand that when I turn down their offers to watch him. They don't realize that I'm looking out for their safety and their things. I never know how he'll behave and they don't get how destructive and how dangerous he can be.

Mother of a fourteen year old:

It is amazing how your expectations change. We'll be happy if she graduates from high school - never mind college. The worry about what will happen later never goes away.

Mother of a fifteen year old:

We've been in a million meetings for my son and they don't know what to do. We've been going around in circles so they point the finger at us. I feel that for the past two years my head has been in a garbage disposal turned on, and my husband feels that same way. Every day has been like hell.

Someone is supposed to come into our house and do family therapy which I'm just a little apprehensive about. It's hard for me to be honest about stuff. It's a little scary here (a family run support group), but I feel like I can trust you guys. I'd love to see a shrink but I'm just afraid DSS will say, Oh she's mental. Let's go lock her up too.

This has affected my whole life. I'm really depressed every day. It's so hard to keep going. I'm glad that my daughter is not like my son because she kind of keeps me going. She's 14. She's starting to have some problems in school now just from stress. I go to work every day now and I'm just a zombie because I can't really focus. Not just because of ADD and whether I have it, I really think I do, but because of all these problems. I get these phone calls at work or, even if I don't I'm just really depressed and freaked out about everything, every day. It's really tough.

Mother of a Nine Year Old

It's hard to let my son go to school every day where I don't feel they understand him. The principal told me, at one meeting, she'd never know he had difficulties if I hadn't brought it to their attention. I picked up the journal my son wrote in school and asked her if suicidal and homicidal entries were considered normal in her opinion. She became very quiet.

This from the same school that turned my son down for Special Ed. services at a team evaluation. He was hospitalized in a Children's

Psychiatric Unit at the time of the meeting, but their finding was that his “disability does not affect his ability to progress effectively in regular education”. I got his report card the next week with three failing grades. When are schools going to learn this is an issue of a human being, not a budgetary issue?

He channels his stress very differently at school than at home. When he gets home, where he feels “safe”, the violent episodes often begin. Sometimes I feel like a battered woman at the hands of my own child. The school manages to turn that around too and claims he must be in a “bad situation” at home to cause the negative behavior. I wonder why five years of working with various professionals still has not led to any validation of that claim. I’m sick of being judged and blamed for a chemical imbalance in his brain. I work hard with and for my son and once in a while I’d like to have a professional validate my efforts.

